Pediatric Acquired Brain Injury in Iowa: Recommendations from the Pediatric Brain Injury Summit

March 7, 2012

Report Prepared by

Megan Hartwig, M.H.A., Iowa Department of Public Health

and

Scott Lindgren, Ph.D., University of Iowa Children's Hospital

Brain Injury is the leading cause of death and disability for children and youth under the age of 25. Each year, traumatic brain injury in the United States causes 12,535 deaths, 80,000 hospitalizations, and 643,000 Emergency Department visits for those under the age of 25 (based on data from the Centers for Disease Control and Prevention). Every day in Iowa, 6 people will have a brain injury serious enough to require hospitalization, 2 of those 6 people will be school-age children, and 1 of those 6 people will die from the injuries. These brain injuries can take many forms. Young brains can be injured by a loss of oxygen, an infection, a stroke, or a blow to the head, and all of these conditions are referred to as "acquired brain injuries." Although a number of services for children and youth with brain injury are available in lowa, access to appropriate supports and services is inconsistent, and families are often frustrated in obtaining the services they need.

On March 7, 2012 the Iowa Department of Public Health (IDPH) partnered with the Brain Injury Alliance of Iowa (BIAIA) and the University of Iowa's Center for Disabilities and Development (CDD) to bring stakeholders together to discuss the issue of pediatric brain injury in Iowa. The one-day summit was made possible with funds from the Traumatic Brain Injury (TBI) Implementation Grant from the Health Resources and Services Administration. Participants included parents of children with brain injuries; Area Education Agency (AEA) staff; members of the Governor's Advisory Council on Brain Injuries (ACBI); staff from BIAIA, CDD, UI Children's Hospital, the Department of Human Services (DHS), and IDPH; and other interested parties. The goal of the summit was to identify barriers to brain injury services for children in Iowa, including those in educational settings, as well as to identify potential solutions to problems identified

The needs of children and youth with brain injuries are wide-ranging. Treatment is often initially provided in an emergency department. Those children with mild injuries may be closely observed and then discharged to home. Some minor head injuries may not receive any medical care at all. When a child is unconscious and in a coma, they will require hospitalization until they are medically stable and alert. Medical care to maintain breathing, nutrition, and seizure control may also be needed. It is important to realize that there may be lasting effects from any of these injuries including those which are not treated.

Over 90% of children with significant brain injuries are discharged to their homes and may receive outpatient rehabilitation services (including speech-language therapy, occupational therapy, and physical therapy). More severely impaired patients may spend time in a rehabilitation hospital to help speed the recovery process or to deal with problems that cannot be managed in the community. Children with severe impairments often need therapy services to regain speech, improve memory and attention, and relearn the motor skills required to walk, talk, eat, or write. Assistive devices may be needed for communication or ambulation, and these devices may include speech production hardware/software, orthotic devices (e.g. braces), and wheelchairs or walkers. A child's return to school may be complicated by the needs for educational accommodations, shortened school days, individual tutoring, adapted assignments, and additional time to complete work due to slow processing speed. Young

adults who are already in the workforce may require both physical and cognitive rehabilitation, as well as individualized accommodations and supports, in order to return successfully to work.

The most common long-term effects of a brain injury include problems in cognition (especially in memory, new learning, and processing speed) and changes in mood or behavior (especially problems in self-control, planning, and other "executive" functions). Physical problems may include rapid fatigue, seizures, headaches, hearing or vision impairments, or motor problems. These problems often decrease over time if appropriate interventions are provided, but disabilities can become chronic if they are ignored and left untreated.

Recognition of the scope and urgency of the problem of pediatric brain injury has resulted in the development of the Pediatric Acquired Brain Injury (PABI) Plan, which is a part of a national initiative to develop a comprehensive, coordinated, and seamless service system for children and youth (up to age 25) who have sustained an acquired brain injury. This initiative was developed by a large and diverse team of national experts in pediatric brain injury who serve on the advisory board for the Sarah Jane Brain Foundation. Systems of care in the PABI plan are organized around seven categories of care that include prevention, acute care, reintegration/long-term care, adult transitions, mild TBI, telehealth, and a virtual center for data and information sharing. The plan would provide support to ensure that these categories of care are available to families and to create an effective care coordination system for each state. The national PABI plan can be accessed at the following link: http://www.thebrainproject.org/pabihome.php.

The strategies outlined in the national PABI plan were reviewed by Summit participants with the understanding that this plan can form a strong foundation for a state plan to meet the needs of lowa children and youth with brain injury. Participants agreed that it is time for lowa to create a system of care that recognizes the comprehensive needs of children and youth with brain injury and ensures that all lowa children receive the services and supports they need. The following priorities reflect recognition of the actions that are needed to create a coordinated and seamless "system of care" for children and youth with acquired brain injury.

Participants were requested to rank the importance of the 10 PABI plan strategies. Participants then discussed critical issues in Iowa related to each of the strategies. Following is a list of ranked strategies with priority issues and recommendations. The recommendations will used to help develop Iowa's State Plan for Brain Injury 2013-2017.

1. Coordinated System of Care (it is important to note that Coordinated System of Care was identified as a priority issue across all issue topics)

Priority Issue	Recommendation
Education and support for medical providers, service providers, teachers and school staff, and families	 Specialized brain injury training made available to anyone who is working with a child with brain injury. Develop family training and support programs covered under Medicaid and the HCBS Brain Injury Waiver. Develop Pediatric Brain Injury Support Groups through the Brain Injury Alliance of Iowa.
Critical service components needed to provide coordinated care	 Provide financial support for brain injury consultation services at the Center for Disabilities and Development at the University of Iowa. Increase funding for the Iowa Program Assistance Response Teams (I-PART) to enable the hiring of more staff to include a brain injury specialist position. Support care coordination for pediatric brain injury through the Child Health Speciality Clinic (CHSC) network.
Lack of coordination within families	 Fund brain injury care coordinator positions who address family issues including providing education on how to work with other family members. Develop a peer support/mentor program for siblings of children with brain injury. Develop a pediatric Neuro Resource Facilitation program.

2. Reintegration/Long-term Care

Priority Issue	Recommendation
Coordination of services for reintegration into home/community	 Develop positions for Family Navigators for brain injury in Iowa. Develop reintegration teams for schools to include medical staff. Require AEAs to support Brain Injury Resource Teams to provide education, support, and protocols for schools working with children with brain injury. Fund transition planning for increased support and services. Increase communication between school nurses and physician offices.
Assessment for waiver services	 Revise assessment for the HCBS Brain Injury Waiver (current assessment does not reflect function and many children are losing waiver services).
Discharge from medical services	 Medical staff should begin discussing discharge throughout treatment process to allow families more time to secure necessary services.
Educators/Education	 Require brain injury education for teachers annually. Provide integration of rehabilitation and educational services. Integrate Occupational Therapy, Physical Therapy and Speech Therapy into school setting to increase access to rehabilitation services.
Ongoing education for community service providers	Provide and increase ongoing brain injury education for community service providers to combat high turnover rates in staff.
Respite	Provide additional sources of respite care for children with brain injury.

3. Policy and Funding

Priority Issue	Recommendation
Focus on Brain Injury, not Traumatic Brain Injury vs. Acquired Brain Injury	Encourage programs like HRSA to support work with all individuals with brain injury and to not focus only on those with TBI.
Brain Injury resources within the AEAs	 Update AEA charters to include brain injury. Increase funding for Brain Injury Resource Teams (BIRT) including AEAs seeking out private foundation funding. Create Brain Injury Specialist positions within the group of behavioral specialists in the AEAs. Require brain injury training for AEA staff. Increase state funding to AEAs to provide brain injury services. Require Brain Injury Specialists to be at IEP meetings for children with brain injury.
Expand access and training	 Increase access to behavioral services on HCBS Waivers. Expand Board Certified Behavior Analyst (BCBA) programs in Iowa. Offer an annual one-day pediatric brain injury conference.

4. Adult Transition

Priority Issue	Recommendation
Access to adult services	Ensure adult services are available in all communities throughout
	lowa.
Transition planning and	Require transition planning for adult services to begin at age 16;
services	encourage peer support and vocational rehabilitation.
	Require specialized case management for HCBS Brain Injury
	Waiver.

5. Acute Care

Priority Issue	Recommendation
Access	 Expansion of licensed acute/post-acute inpatient care for pediatrics. Increase opportunities for education from medical staff surrounding diagnosis of brain injury. Fund expansion of Iowa Brain Injury Resource Network (IBIRN). Fully fund the HCBS Brain Injury Waiver to eliminate the waiting list for services. Address communication issues surrounding the Medicaid program for children with special needs (this service is not always communicated to families).
Workforce	 Recruit more pediatric brain injury providers across all service delivery programs. Develop a forgivable loan program for individuals committed to working with children with brain injuries. Encourage communities to pay for provider education.

6. Deciding What Works (Research)

Priority issue	Recommendation
Limited outcome data	 Include outcome data and evidence-based approaches into plans for brain injury services. Support research that focuses on optimizing outcomes after brain injury
Resources	 Expand information distributed in Iowa to include new sources (IBIRN tote bags). Promote the dissemination of CDC concussion information and toolkits.

7. Rural/Telehealth

Priority Issue	Recommendation
Opening access to out of state specialty providers	 Recognize licensure from other states to allow for Medicaid/insurance reimbursement for services.
Limited telehealth/rural services	 Expand telehealth services for in-state providers. Expand the use of telehealth services for IEP meetings, consults, team conferences, etc. in education settings. Develop a "best practice" resource for release of information issues surrounding telehealth.
Not enough qualified individuals to provide follow-up telehealth consults	 Expand access to qualified individuals to follow up on telehealth consults. Ensure funding for care delivered via telehealth, including behavioral services

8. Data & Information Sharing

Priority Issue	Recommendation
Sharing resources that work	 Library of stories, IEPs, plans, factsheets, etc. with successful approaches and information regarding pediatric brain injury.
Need to update state data sets to include what services were provided to each individual who has been injured.	Include a surveillance component into Electronic Health Record system
Lack of sharing across data sets (DHS/Medicaid/IDPH/Dept. of Education) consistent with the Health Insurance Portability and Accountability Act and the Family Educational Rights and Privacy Act	 Include option for families to voluntarily include secondary data on IEPs. Develop simple release of information forms that permit data sharing across government agencies and medical care facilities
Outcome studies	 Determine the most important data sets statewide and require reporting across all systems.

9. Mild Traumatic Brain Injury

Priority Issue	Recommendation
Youth Concussion	 Expand lowa youth concussion legislation to include all club sports and elementary school-age children. Require all youth sports participants to undergo pre and post testing using a computerized system (e.g., IMPACT). Require healthcare providers to educate families on home treatment to include symptoms to watch for and require a scheduled follow-up appointment. Require additional equipment mandates, including face masks.
Mental Health and Criminal Justice	 Identify children with mild TBI earlier and provide services to decrease unnecessary criminal justice and mental health involvement.

10. Prevention

Priority Issue	Recommendation
Shaken Baby Syndrome	 All health care providers should be required to watch the video "The Period of Purple Crying". All parents should be provided a copy, a link, or a showing of the video "The Period of Purple Crying" after the birth of their baby.
Youth Helmets – moped/motorcycle	 A universal helmet law should be passed into law. If a universal helmet law is not implemented, youth who are 17 and under should be required to wear a helmet when operating motorized recreational vehicles including ATVs, motor-scooters, mopeds, and motorcycles.
Enhancements to the Graduated Driver's License	 The number of non-family members allowed in the car should be limited.
Early identification to provide services and prevent secondary injuries	 Require brain injury education for first responders, Emergency Department staff, and primary care providers. Require first responders, Emergency Department staff, and primary care providers to screen for TBI. Add additional focus on brain injury during pre-natal healthcare, well-child screenings, etc. Increased education for healthcare staff regarding looking at potential brain or head injuries when evaluating other physical issues during exams.